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ABSTRACT

The Education of the Handicapped Act Amendments of 1986 provide for early intervention services to children with special needs and their families. Part of the amendment requires that early intervention programs develop an Individualized Family Service Plan (IFSP) for each child. These plans require that families participate in defining the child's intervention program. This article discusses the problems that arise in assessing family strengths and needs, identifying resources, and empowering parents. Issues of collaboration between parents and professionals are considered particularly difficult, and their success crucial. The article considers issues such as re-training and re-education of early intervention professionals, re-vamping old intervention programs to make them more family-centered, and changing the established mindset of professionals and parents. Guidelines for best practice for professionals to achieve these cooperation goals are suggested. Contains 20 references. (JPB)

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Parent-Professional Partnerships in Family Focused Intervention

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Abstract

The Education of the Handicapped Act, Amendments of 1986 (Public Law 99-457, Part H) provides early intervention services to children with special needs (from birth through two) and their families. The law recognizes the influence of parents on the development of their child and mandates that parents should be part of the multidisciplinary team that decides services for their child. Despite good intentions, however, the transition of the professional from the role of the expert to working with parents as equal partners has been laden with difficulties (Minke & Scott, 1995).

Part H of P.L. 99-457 requires that early intervention programs develop an Individualized Family Service Plan (IFSP) for each child and her/his family. IFSPs empower families by redefining them as the primary service recipient and enabling parents to play an active, integral role in their child's intervention program.

However, developing IFSPs, assessing family strengths and needs, identifying resources, and empowering parents are tricky issues (Bailey & Blasco, 1990). The interaction, collaboration, and partnerships between families and professionals that are necessary to develop and implement IFSPs are crucial to providing appropriate services to a child with special needs and his/her family. Issues such as re-training and re-education of early intervention professionals, re-vamping old intervention programs to make them more family-centered, and changing the already established mind-set of professionals and parents need to be considered (Apter, 1994).

Family-focused or Family-centered Intervention

Research examining family functioning indicates that due to the transactional nature of families, each member of the family influences, and is influenced by, the others. Therefore, trying to understand a particular family member (in this case, the child with special needs) requires a more holistic approach, that is, an understanding of the entire family (Caro & Derevensky, 1991; Skrtic, Summers, Brotherson, & Turnbull, 1984). Family-focused or family-centered intervention comprises the following three principles: (a) family-centered practice; (b) active involvement of the family; and (c) strengthening family functioning (McBride, Brotherson, Joanning, Whiddon, & Demmitt, 1993). Family-centered practice considers the family to be at the focus of services. Interventions include an assessment of the strengths and needs of the entire family. The intervention focus also includes outcomes and services for the children, as well as their families (Krauss, 1990; McGonigel, Kaufmann, & Johnson, 1991). Active involvement of the family in the decision making process is the second key principle of family-centered intervention (Bailey, 1987). Parent involvement, formerly used to denote passive review and approval, has evolved to include active parental participation on the multidisciplinary team. Family members are treated as partners with professionals and have the authority to make all important decisions concerning their child and family (Apter, 1994; Dunst, 1991; Krauss, 1990). Strengthening family functioning by providing appropriate intervention services is the third overarching principle of family-centered intervention. Services for children and families should equip them with befitting resources that will result in increased competencies which support and strengthen families (Dunst & Deal, 1994).

Developing the Individualized Family Service Plan

The Education of the Handicapped Act Amendments of 1986 (Section 677) mandates that each toddler or infant with special needs and his/her family must receive a written individualized family service plan (IFSP) developed by a multidisciplinary team that includes professionals as well as parents or guardians. The IFSP must contain a statement of the child's present levels of physical development, cognitive development, language and speech development, and self-help skills, a statement of family strengths and needs, and a statement of specific goals and services with desired outcomes for the child and the family. The purpose of the IFSP is to enable professionals and families to work together and create a meaningful partnership to identify resources that help families reach their chosen goals. The process of creating the IFSPs, therefore, is just as important as the final product itself.

Developing an individualized family service plan takes time, effort, and collaboration between professionals and parents. A family-centered approach to developing IFSPs has been devised by Dunst and Deal (1994). Their family-centered intervention model takes into account the following eight essential elements that are instrumental in strengthening and empowering families.

- Family concerns: This includes areas of interest or importance associated with the functioning of the family unit or the individual family members (e.g., parents' reaction to the news that their child has a developmental disability).
- Family needs: This includes the desire or necessity for resources that would help the child and the family to meet their goals (e.g., request for professional opinion about the child's potential for improvement).

- Outcome statements: This is a statement of how the identified needs or concerns will be met (e.g., parents will make an appointment for a developmental assessment).
- Resources and supports: This includes a range of options such as types and sources of assistance, advice, and information for meeting the identified needs (e.g., early childhood professional will conduct a child assessment and apprise the parents of the child's prognosis).
- Courses of action: A series of steps that will be taken so that the family is able to procure resources and supports to meet the identified needs (e.g., parents and early childhood professional will meet to discuss implications of the child's diagnosis for the child and the family, appropriate intervention services will be targeted).
- Family strengths: This includes knowledge, skills, and capabilities of each family member as well as the family as a unit (e.g., parents' knowledge about the child's impairment and ways to deal with it).
- Partnership: This is about collaboration between a family and a professional using established roles that will facilitate the acquisition of the desired resources and supports (e.g., combining information from the professional's child assessment and knowledge of the child from the parent's perspective to decide upon appropriate intervention services).
- Evaluation: Determination of whether the desired resources and supports were obtained to the family's satisfaction (e.g., whether the parents felt that their needs and concerns were addressed adequately).

Family and team issues in implementation of P.L. 99-457 (Part H):

Although laws and policies concerning children with special needs and their betterment acknowledged the importance of the family, traditional services have focused on the child, not on the entire family. Public policies for children with special needs and their families typically rationed their services so that only those who are in dire need of help and have depleted all their resources are covered. The result was automatic exclusion of families with the focus only on the child with special needs. Families differ in their needs, and often family members go to extraordinary lengths to secure services for their child while maintaining the upkeep of the family unit. Moreover, a traditional cultural hesitance to intrude on the privacy of these families was reflected in the governmental policy makers' reluctance to design and support preventive family programs. Hence, policies have predominantly focused solely on the child, with the system planners being the expert, and the child being the primary service recipient in early intervention programs (Krauss, 1990; McGonigel & Garland, 1988). P.L. 99-457 moves away from tradition and into the hitherto uncharted territory of "family focused" or "family centered" intervention.

According to Part H, families are central to the determination of services for their child. The new system recognizes and respects the unique influence that the parents have on their children's growth and development (Able-Boone, Sandall, Loughry, & Frederick, 1990; Krauss, 1990; Mahoney & O'Sullivan, 1990; McGonigel et al., 1991). Best practice recommendations are shifting from parent participation to services that involve the entire family. However this transition has been difficult for parents as well as professionals. A recent study of parent-professional relationships suggests that bonding

between parents and staff is an important element (Minke & Scott, 1995). Specifically, parents appreciated the emotional support and encouragement they received, while staff members noted easier joint problem solving, greater acceptance of program shortcomings, and increased willingness on behalf of the parents to try new behaviors. While voicing support for a family-centered model, professionals also expressed reservations about forming relationships and collaborating with parents. Balancing dependence and independence in a parent-professional relationship, loss of professional control and whether all families have the skills required for collaboration and can participate fully despite limited technical knowledge and unrealistic expectations were concerns that were raised by professionals. Some staff members also questioned the capability of some families to act in the best interests of the child. Findings such as these suggest that although the trend toward family-focused intervention has definitely begun, some professionals still have difficulty in coming out of the "expert" role and assuming the "collaborator" role. Below are family and team issues in implementation of P.L. 99-457 (Part H):

Interpreting the law: While Public Law 99-457, the Education of the Handicapped Act Amendments of 1986, was being developed, there was almost total agreement within the field on several critical issues addressed in the bill (McGonigel & Garland, 1988).

Nonetheless, now that the law has been implemented, it is not without controversies.

Specifically, which family strengths and needs should be identified? How does one go about identifying them? How do we determine which family needs are directly related to the development of the child with special needs and which are not? Clearly, some problems such as serious marital conflict or chronic personality problems influence the

child, but they are beyond the skills and resources available in the early intervention program. However, when perceived to be problematic by both families and professionals, the staff and family can work together to identify resources in the community that can address these issues and help families work toward their goals (Summers, Dell'Oliver, Turnbull, Benson, Santelli, Campbell, & Siegel-Causey, 1990; McGonigel & Garland, 1988). Additionally, existing funding mechanisms that provide fiscal support to early intervention providers need to be revamped (Apter, 1994).

Shift in philosophy for professionals: A shift in philosophy for professionals involves re-training and re-education of early intervention professionals, re-vamping old intervention programs, and adjusting the already established mind-set of professionals to become more family-centered. Identifying the eligible population, defining case management, ascertaining relevant services, and understanding the meaning of being "family-centered" are issues that need to be resolved (Apter, 1994).

Shift in philosophy for parents: A shift in philosophy for parents requires changes in the way families interact with professionals, in that, parents must realize that they have the capability to help their children reach their fullest potential, and they must take responsibility for doing so (Apter, 1994).

Parent-professional partnerships: Creating meaningful parent-professional partnerships involves including parents in every aspect of the IFSP process. Professionals need to be sensitive, respectful, supportive, flexible, non-judgmental, and acknowledge families as the ultimate decision makers (Summers et al., 1990).

Cultural sensitivity: Not recognizing cultural diversity can lead to incorrect assumptions about the family and limit the effectiveness of the early intervention program (Beckman

& Bristol, 1991). If we are to provide appropriate early intervention services for every child, including children from different cultural backgrounds, then professionals in the field must recognize the diversity of the families with whom they work. Furthermore, professionals must understand and appreciate the values and belief systems of diverse families and demonstrate respect for differing values across cultures. Early intervention professionals need to be aware of how their own cultural orientations affect their actions, and similarly, how the family's culture influences its participation, communication and relationship development with the professionals (Gallagher & Desimone, 1995).

Guidelines for best practice in the field of early intervention

The following are some suggestions for best practice for professionals in the field of early intervention.

Provide information: Factual information about the child's needs, gaining access to and monitoring available services; behavior management, services for the future, and contact with families whose children have similar needs enable parents to feel in control.

Provide assistance: Provide help with responding to others questions (especially children) about the condition of the child, basic expenses, appropriate care-giving alternatives, money and time management.

Provide support: Establish a rapport with the family, acknowledge individual and family preferences, be flexible, communicate clearly, and provide emotional and social support (Summers et al., 1990).

Provide an impetus: Encourage family members to participate by providing incentives such as child care support, financial reimbursement, continuing education credits, and

opportunities to relax and obtain companionship outside the family (Winton & DiVenere, 1995).

Collaborate with families: Encourage parents to be their child's *co-case managers* (Able-Boone et al., 1990). Engage in joint problem-solving and work with parents to access and utilize resources.

Involve families: Encourage family members to conduct workshops for other families or students, be preservice and inservice instructors, active team participants in staff development, planners and policy makers.

Recognize and respect familial and cultural diversity: Respect values, beliefs, and practices of all cultures, involve people from different cultural backgrounds on the early intervention teams, provide materials and/or interpreters in the family's primary language, and seek help from other families of the same culture to enhance communication between parents and professionals (Lynch, 1987).

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